DARE TO CARE
WHERE DATA MEETS VOICES OF THE AUTOIMMUNE COMMUNITY

EPISODE 1:
BALANCING ENERGY, WORK & PRODUCTIVITY TO THRIVE WITH AUTOIMMUNE DISEASES

REPORT

Living with a rare autoimmune disease like Myasthenia Gravis (MG) or Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) affects more than just physical health: it impacts careers, relationships and daily routines. In the first episode of the Dare to Care webinar series, patients, experts and advocates came together to explore the realities of managing professional life while navigating the unpredictable challenges of neuroautoimmune diseases such as MG and CIDP.

This report highlights key insights from the discussion, emphasizing the hidden nature of these conditions, their daily impact, and the vital role of caregivers and employers in balancing energy, work, and productivity while living with a rare autoimmune disease.

"For me it's primarily muscle weakness in my hands and face. It's completely invisible but come and live with me for 10 days and you'll notice."
Matthieu, MG Patient.

"It's complicated and an overburden to have to explain the invisibility part of the symptoms"
Jean-Philippe, CIDP Patient.

"Do people need external signs to understand the severity of an illness? You should not judge people based on what you can see."
Marguerite, MG Patient.

1. INVISIBLE, UNPREDICTABLE & CHALLENGING

Living with a rare and invisible disease like MG or CIDP means **a delicate**, and often **misunderstood reality**. The symptoms aren't always visible, but **they are profoundly real**. These conditions challenge not only the patients' daily lives, but also the perception of others—forcing patients to constantly explain or **justify their struggles**. Considering the unpredictability of these diseases, the situation becomes even more complex.

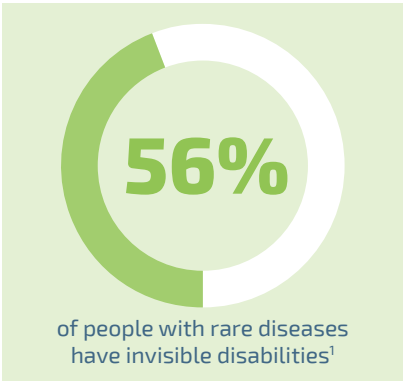
NAVIGATING THE INVISIBILITY OF SYMPTOMS: A SHARED RESPONSIBILITY

Invisible symptoms are often harder to detect externally but deeply impact the daily lives of those living with MG or CIDP. During the discussion, **patients emphasized the need for healthcare professionals to go beyond what's visible and truly listen. Recognition and validation** of these symptoms are essential for delivering **empathetic, holistic care.**

At the same time, sharing these invisible aspects can be emotionally complicated for patients. Matthieu, MG patient, spoke of the fear of being seen differently, treated with pity or perceived as less capable. **Patients often balance the desire for support with the need to appear 'normal'.**

The discussion made it clear: **tackling invisibility requires trust and openness on both sides: healthcare professionals who ask and listen and patients who feel safe enough to speak up.**

As Caroline Collard, Patient Care Expert, underlined: **"It's important to remember that each person is different. One size fits nobody."** What works for one patient may not help another, and even for the same individual, symptoms can fluctuate daily. **Each experience is unique, making diagnosis, treatment and support a deeply personal journey.**



of people with rare diseases have invisible disabilities[1]


Jean-Philippe and Matthieu, CIDP & MG Patients.

"Little things take so much energy that there is not enough left for the big things. Small activities sometimes can ruin your whole day." **Matthieu, MG Patient.**

"It's like having muscle pain all the time. Holding a plate or brushing my teeth hurts. It's mentally and physically exhausting." – **Jihane, MG Patient.**

"In my daily life, it can, for example, be challenging to dress myself, to put on a suit, or to shave myself: all very simple things." **Jean-Philippe, CIDP Patient.**

2. DAILY LIMITATIONS CAN DRIVE SOCIAL ISOLATION

For people with MG or CIDP, even the **basic daily tasks** (holding a cup, brushing teeth, walking up the stairs) **can feel like hiking insurmountable mountains**. Muscle weakness, fatigue and other fluctuating symptoms strip away the ease of daily life, leading to a deep sense of frustration and, often, a loss of autonomy.

Beyond the physical impact, the journey to diagnosis is equally challenging. These diseases are rare and complex, making them difficult to identify quickly. Many patients endure long periods of misdiagnosis or dismissal, adding emotional strain to an already heavy physical burden. Early recognition and greater awareness are essential steps toward better outcomes and quality of life.

TACKLING THE UNPREDICTABILITY OF MG AND CIDP: PLANNING, FLEXIBILITY, AND EMPATHY

Living with MG or CIDP means navigating a life where no two days feel the same. The **symptoms don't follow a script**, they fluctuate. Sometimes without warning, **turning ordinary moments into unexpected challenges.**

During the discussion, patients emphasized the importance of **planning as a coping mechanism**. As Matthieu, MG patient, put it: "**We are extreme super planners**. You plan to avoid unpredictability based on the 'workload' you know you can take on in a day."

This kind of planning isn't just about schedules. It's about **preserving energy, managing expectations**, and **maintaining a sense of control**. But even the best-laid plans can be upended by the nature of the disease.

DATA INSIGHTS

SELFCARE

48%
of people with MG experience difficulties with brushing teeth and combing hair[2]

50%
of people with CIDP experience arm disability including brushing hair[4]

WALKING

55%
of people with MG experience difficulty walking[3]

34%
of people with CIDP experience difficulty walking[5]

"The disease is so fluctuating that you can be out for a week, two weeks, or even a month or longer at once."
Jihane, MG Patient.

"I had to reconsider my professional path and became a freelancer but now it feels a bit like a golden prison."
Matthieu, MG Patient.

"CIDP impacts my motor skills. A nurse needs his hands to work. That's why I didn't wait to see the disease progress and proactively changed careers."
Jean-Philippe, CIDP Patient.

"I was self-employed, a real workaholic, but when my contract wasn't renewed, it made sense. Who wants to hire someone who is unpredictable?" –
Alejandra, CIDP Patient.

DATA INSIGHTS

LIMITATION OF WORK & PRODUCTIVITY

70%
of people with MG or CIDP experience limitations in their work and productivity due to their disease[6,7]

MISSING WORK

41%
of people with MG miss work regularly due to their condition[8]

32%
of employed people with CIDP reported work absenteeism due to their condition[9]

RETIREMENT

42%
of people with CIDP have no full-time employment or had to retire early[10]

11%
of people with MG had to retire early due to their condition[11]

3. DOES WORK STILL WORK?

For many patients with MG or CIDP, **work (in the sense of employment)** isn't just about career aspirations, it's about **maintaining independence and a sense of normalcy**. However, the unpredictable nature of some autoimmune diseases raises difficult questions: **Should patients adapt their job to fit their condition, or must they leave their profession altogether?**

Fluctuating, often severely debilitating symptoms, frequent medical appointments, and periods of extreme fatigue can make **traditional work structures challenging**. Without employer awareness and flexibility, many patients struggle to keep up or are forced out of the workforce. **Finding the right balance between health and professional life requires understanding, adaptation and support from both patients and employers.**

ADAPTING WORK OR CHANGING JOBS: NAVIGATING EMPLOYMENT AFTER DIAGNOSIS

A diagnosis of MG, CIDP, or other neuroautoimmune diseases can **reshape an entire professional life.** The question many patients face is tough: ***Do I need to change my job, or can my job change with me?***

As Jean-Philippe, CIDP patient, shared: **"Both. It depends on the job.** If you rely on your body for work, it's much harder to adapt than if your work primarily involves cognitive tasks. **In an ideal world, employers should support workers with rare diseases."**

For many, the goal isn't to leave work behind: it's to **stay engaged, empowered, and effective.** That might mean flexible hours, assistive devices, or a new role that fits current abilities. But the **key ingredient is collaboration. Patients and employers must explore solutions together.**

And when it comes to invisible symptoms, **awareness is everything.** As Caroline Collard, Patient Care Expert, pointed out: **"If the employer doesn't know, they can't act on it.** In a fast-paced society full of assumptions, **honest conversations about limitations and strengths, can change the game."**

Matthieu, MG patient, captured this perfectly: "Being a patient doesn't make you less valuable at work. **You might lose some abilities, but you gain new strengths."**

The bottom line? With the right support and a willingness to adapt, people living with rare autoimmune conditions can **continue to thrive at work: not in spite of their condition, but alongside it.**

"Take care of your caregivers because they are incredibly precious. The minimal caregiving I require still has a significant cost to my partner because I always feel indebted. She's not just there for my care; she's my partner, the person I live with, the mother of our children." - **Matthieu, MG Patient.**

4. CARING FOR CAREGIVERS

Behind every patient, there is often an unsung hero: a caregiver. Most caregivers are **family members: partners or even children**, who step in to provide daily support, ensuring their loved one can manage the challenges of MG or CIDP.

Their role extends beyond physical assistance; they offer emotional strength, advocacy, and stability in an unpredictable journey. But **caregiving comes with its own sacrifices, requiring time, energy, and often major life adjustments.** Recognizing their dedication and addressing their needs is just as important as supporting the patients themselves.

CARING FOR THE CAREGIVER: THE OTHER SIDE OF THE PATIENT JOURNEY

Caregivers provide daily physical and emotional support, but often at a personal cost. As Dr. Sarah Dewilde, Public Health expert, shared: "Caregivers feel a **loss of independence, lack control over their own lives.** While they support others mentally and physically, **their own wellbeing worsens compared to the general population."**

Jean-Philippe, who has lived with CIDP for 25 years, reflected on the emotional weight: "My wife has been supporting me for 25 years now. But **I try not to be a burden on her.** She didn't marry someone who would need help with simple daily tasks."

This care dynamic runs deep. While patients often feel indebted, **caregivers may struggle to voice their own needs.** That's why it's essential **to create spaces where caregivers can be heard, supported, and recognized**; not just as helpers, but as individuals navigating their own emotional landscape.

As Jean-Philippe put it: "We have to understand the burden of the caregiver and **create opportunities for them to express their voices.** These are also **great moments for patients to be the caregiver of their caregiver**, for a brief change."

Patient organizations play a key role here: offering tools, communities, and emotional resources not just for patients, but for those who walk alongside them every step of the way. Because care is not one-sided: **it's a shared, evolving partnership.**

DATA INSIGHTS

CAREGIVERS' SUPPORT

27%
of people with CIDP[12] require support from a caregiver

32%
of people with MG[13] require support from a caregiver

CAREGIVERS' WORK STATUS

41%
of CIDP caregivers[14] changed their work status due to caregiving

31%
of MG caregivers[15] changed their work status due to caregiving

5. IN A NUTSHELL: KEY TAKEAWAYS

FOR THE PATIENT

- **Patients' struggles are real, even if invisible** and advocating for themselves is essential.
- Fatigue, muscle weakness, and daily challenges require **careful planning and self-care.**
- Seeking support from **patient organizations can help navigate work, daily life and mental health.**
- With the right support, adaptation and open communication, **patients can continue to thrive and bring unique strengths to the workplace.**

FOR THE CAREGIVER

- **Caregivers play a crucial role**, often dedicating up to 30 hours per week to care[16].
- **The well-being of caregivers is just as important,** so they shouldn't hesitate to seek help and respite.
- **Open conversations** with patients can ease the emotional burden for both sides.

FOR THE HEALTHCARE PROFESSIONAL

- **Faster diagnosis is critical** and **listening to patients'** descriptions of symptoms is key.
- A **multidisciplinary approach to care** (doctors, nurses, physiotherapists, psychologists, etc.) leads to better patient outcomes.
- **AI and specialized tools can help improve early detection and care strategies.**

FOR THE EMPLOYER

- **Adapting** the **workplace** creates a more **inclusive and productive environment.**
- **Open discussions** about invisible illnesses **reduce stigma** and allow **employees to thrive.**
- **Small adjustments** (flexible hours, remote work options) **can make a big difference, while maintaining productivity** and enhancing the employee's strengths.

TO CONCLUDE

Thriving with autoimmune diseases: a call for holistic care

Living with an autoimmune disease means adapting in every aspect of life - physically, emotionally, socially and professionally. To navigate these challenges, patients and experts emphasize the need for **a holistic approach to care**, one that goes beyond medical treatment, to integrate:

Open conversations with employers and tailored work arrangements empower individuals to contribute meaningfully while managing their health.

By combining education and real-world data, we can reshape workplace culture and healthcare systems, valuing people for their strengths rather than defining them by their condition.

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INTERESTED IN LEARNING MORE?

Watch the first episode of 'Dare to Care' – the new webinar series by argenx -
to hear expert insights, patient stories, and strategies for balancing energy, work and productivity.

https://argenx.com/events/dare-to-care

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1. EURORDIS (2025). Rare Barometer Survey: Recognising disabilities and barriers. https://download2.eurordis.org/rarebarometer/RB_DailyLife_FS_Europe_EN.pdf (survey sample: 9,591 individuals living with a rare disease or their family members across 43 European countries, representing 1,643 rare diseases). Data explanation: Among people with rare diseases who have disabilities (80% of all rare disease patients), 70% live with an invisible disability.

2 & 3. Dewilde S., Philips G, Paci S, et al (2023), Patient-reported burden of myasthenia gravis: baseline results of the international prospective, observational, longitudinal real-world digital study MyRealWorld-MG, BMJ Open 2023;13:e066445. doi: 10.1136/bmjopen-2022-066445 MyRealWorld-MG study sample: 2,074 adults with myasthenia gravis in 9 countries). In the MyRealWorld-MG study, 29.3% of participants reported needing extra effort but no rest to brush their teeth or comb their hair, 18.1% required rest periods, and 0.9% were unable to perform these activities. Regarding mobility, 45.7% experienced some trouble walking and 9.4% reported severe difficulty.

4. Adelphi CIDP DSP (2022-23) PRF, Section E, Q6a/b (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.). Data explanation: 30% of patients reported having symptoms in one or both arms, affecting the following activities: do all zips and buttons, wash and brush hair, use knife and fork together, handle small coins. 16% of patients reported having symptoms in one or both arms, preventing one or two of the above-mentioned activities, and 4% of patients reported having symptoms in one or both arms, preventing three or more of the above-mentioned activities.

5. Paci, S., Arvin-Berod, C., Brackx, F., Tollenaar, N., Van de Veire, L., Sahar, R., Taylor, Y., Wright, J., deCourcy, J., & Dewilde, S. (2025), Burden of illness and unmet need among patients with CIDP: Results from a real-world survey (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.).

6. Lehnerer S, et al. (2022), Burden of disease in myasthenia gravis: taking the patient's perspective. J Neurol. 2022 Jun;269(6):3050-3063. doi: 10.1007/s00415-021-10891-1. Epub 2021 Nov 20. Erratum in: J Neurol. 2022 Oct;269(10):5688-5689. doi: 10.1007/s00415-022-11290-w. PMID: 34800167; PMCID: PMC9120127 (study sample: 1,660 adults with myasthenia gravis, recruited via the German Myasthenia Association). In the study, among the patients who had previously been employed, 72.6% indicated that MG had limited their ability to work or maintain productivity.

7. Adelphi, CIDP DSP (2022-23), PSC, Section A, Q1-6, Section H Q1-6 (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data). Data explanation: According to physician reports, the impact of CIDP on patients' work or productivity was rated as follows: 20% slightly affected, 24% somewhat affected, 19% moderately affected, and 12% extremely affected..

8. Jacob, S., Dewilde, S., Qi, C., Saccà, F., Meisel, A., Palace, J., Claeys, K., Mantegazza, R., Paci, S., & Phillips, G. (2022). Productivity losses for MG patients and their caregivers: Association with disease severity (MyRealWorld-MG study sample: 834 participants from 7 countries).

9. Paci, S., Arvin-Berod, C., Brackx, F., Tollenaar, N., Van de Veire, L., Sahar, R., Taylor, Y., Wright, J., deCourcy, J., & Dewilde, S. (2025), Burden of illness and unmet need among patients with CIDP: Results from a real-world survey (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.). Data explanation : Among employed patients, 32% reported work absenteeism within the last 7 days due to CIDP.

10. Paci, S., Arvin-Berod, C., Brackx, F., Tollenaar, N., Van de Veire, L., Sahar, R., Taylor, Y., Wright, J., deCourcy, J., & Dewilde, S. (2025), Burden of illness and unmet need among patients with CIDP: Results from a real-world survey (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.). Data explanation: 46% of patients were employed full-time, 12% were homemakers and 42% have no full-time employment (12% working part-time, 30% unemployed/ retired/ long-term sick leave).

11. Dewilde S., et al (2025), A cost analysis of reductions in work productivity for MG patients and their caregivers by symptom severity. Front. Public Health. 13:1538789. doi: 10.3389/fpubh.2025.1538789 (MyRealWorld-MG study sample: 1,049 participants— including MG patients and caregivers with productivity and MG-ADL data—from 10 countries.)

12 & 14. Paci, S., Arvin-Berod, C., Brackx, F., Tollenaar, N., Van de Veire, L., Sahar, R., Taylor, Y., Wright, J., deCourcy, J., & Dewilde, S. (2025), Burden of illness and unmet need among patients with CIDP: Results from a real-world survey (sample: 83 neurologists provided data for 542 patients with CIDP, of whom 199 provided self-reported data. The study was conducted in France, Germany, Italy, Spain, and the UK.).

13. Caregiver burden-MG, Submitted to Orphanet J. Rare Dis. | 2024 & Productivity losses - MG, Submitted to Advances in Therapy | 2024 & Dewilde S, Phillips G, Paci S, De Ruyck F, Tollenaar NH, Janssen MF. People Diagnosed with Myasthenia Gravis have Lower health-related quality of life and Need More Medical and Caregiver Help in Comparison to the General Population: Analysis of Two Observational Studies. Adv Ther. 2023 Oct;40(10):4377-4394. doi: 10.1007/s12325-023-02604-z. Epub 2023 Jul 25. PMID: 37490259; PMCID: PMC10499690.

15 & 16. Dewilde S., Paci S., Mantegazza R. et al. (2025), A cost analysis of reductions in work productivity for MG patients and their caregivers by symptom severity. Front. Public Health 13:1538789. doi: 10.3389/ fpubh.2025.1538789 (sample: 1049 MG patients and caregivers reported on work productivity. Productivity losses were calculated using the average wage per hour. A UK perspective was adopted for the whole sample, and country- specific analyses were conducted for Italy, Spain and the US.). Data explanation: In total, 14.6% of caregivers reported cutting working hours, with an average of 13h cut per week, while 15.5% had to stop working altogether.